

Appendix Table: Brief Index of Lupus Damage Questionnaire

This survey collects information about symptoms you may have experienced related to your lupus. It takes most people about 10 minutes to go through the questionnaire. Please remember that if you are not comfortable answering any question, you can skip the question. The information you give me today is completely confidential. It will not be shared with your doctor or *anyone* outside of the study.

(Responses are recorded as yes, no, or don't know. This last option is not offered, but recorded anytime a respondent is unable or refuses to answer. Interviewer guides are shown in *italics*. Items roughly follow the order of the SDI instrument. Organ system headings are included here for reference only.)

	Scoring/notes
<u>Ocular</u>	
1. Has an eye doctor ever told you that you had something wrong with the retina of your eye because of your lupus? (<i>The retina is the back of your eye</i>)	1
Has a doctor ever told you that you had any of the following conditions or symptoms?	
2. A cataract in your eye?	1
<u>Neuropsychiatric</u>	
3. A psychotic episode?	1
4. Seizures?	
If yes: Did you ever have to take medication for seizures for at least 6 months?	1
5. Stroke?	1
If yes: Did you ever have more than 1 stroke at least 6 months apart?	1
6. Paralysis in your arms or legs that was so severe that you needed to be hospitalized? (<i>note: This is transverse myelitis, a rare condition caused by inflammation of the spinal cord</i>).	
If yes: Was this paralysis from a stroke or multiple sclerosis?	1 point only if 'no'
<u>Renal</u>	
7. Have you ever had a kidney transplant?	3 points if yes to either item 7 or 8
8. Have you ever been on dialysis for 6 months or longer?	
<u>Pulmonary</u>	
Has a doctor ever told you that you had any of the following conditions or symptoms?	
9. Pulmonary hypertension, which is high blood pressure in the lungs? This is different from regular hypertension or high blood pressure. (<i>note: Diagnosis starts with an echocardiogram, not with a blood pressure cuff</i>).	1
10. A serious condition of your lungs, such as fibrosis or interstitial lung disease? This does <i>not</i> include pneumonia, asthma, emphysema, or pleurisy. (<i>note: also not COPD, or bronchitis</i>)	1
<u>Cardiovascular</u>	
11. Have you ever had coronary or heart bypass surgery?	1 point if yes to either item 11 or 12
Have you ever been told by a doctor that you had any of the following problems?	
12. Heart disease, including angina or congestive heart failure?	
13. Heart attack?	1
If yes: Did you ever have more than 1 heart attack at least 6 months apart?	1
14. An episode of pericarditis, which is an inflammation in the sack around the heart, that lasted 6 months or longer?	1

<u>Peripheral vascular</u>	Scoring/notes
Have you ever had any of the following symptoms or conditions because of your lupus?	
15. Loss of flesh or thinning on the ends of your fingers?	1
16. Loss of a finger, toe, or part of an arm or leg? (note: not due to an accident)	1
17. Deep vein thrombosis -- DVT -- or a blood clot in your arm or leg?	1
<u>Gastrointestinal</u>	
18. Have you ever had abdominal surgery because of your lupus? If yes: What part of your abdomen was operated on? (record all) Esophagus..... 1 Stomach 2 Small Intestine 3 Large intestine/colon..... 4 Spleen 5 Liver..... 6 Pancreas 7 Gall bladder 8 Other (e.g. kidney, appendix, reproductive organs) 9 (Note: if 'other' organ listed, probe for additional abdominal surgeries before recording.)	1 pt. for 1 st surgery (excluding 'other') +1 for multiple surgeries
Has a doctor ever told you that you had any of the following conditions or symptoms?	
19. Peritonitis, which is an inflammation of the lining of your abdomen?	1
<u>Musculoskeletal</u>	
20. Deformities of your hand due to lupus? (note: This could be from ligaments in the hand becoming lax, or from rheumatoid arthritis, but NOT [osteo]arthritis, which can also cause deformities.)	Omitted from final version
21. Osteoporosis, or thin bones, that resulted in a fracture?	1
22. Avascular necrosis? This is when part of a bone dies.	1
23. Osteomyelitis? This is an infection in a bone.	1
<u>Skin</u>	
24. Permanent scarring of your skin due to your lupus? (note: This is most commonly due to discoid lupus rash, also from fat inflammation or panniculitis)	Omitted from final version
25. A skin ulcer, which is an open sore on your skin, that lasted 6 months or longer? (note: this is not an oral ulcer or a 'cold sore')	1
<u>Premature gonadal failure</u> Women only	
26. (Age 40+): Did your menstrual periods stop before you turned 40? (if due to hysterectomy, mark dk) (Age <40): Do you still get your menstrual periods? (if pregnant or nursing, mark 'yes')	1
Has a doctor ever told you that you had either of the following conditions?	
<u>Diabetes</u>	
27. Diabetes?	1
<u>Malignancy</u>	
28. Cancer? If yes, What kind of cancer? _____ (list all)	1 (+1 for >1 type), exclude dysplasia

That's all the questions I have. Thanks very much for completing the survey.